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Use of Focus Groups to Inform a Youth Diabetes Prevention Model

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INTRODUCTION

The combined prevalence of diabetes and pre-diabetes in youth has increased from 9% to 23% in the last decade.¹ Pre-diabetes prevalence increases with weight (12% in normal weight, 18% in overweight and 30% in obese adolescents).² If pre-diabetes incidence remains constant, the proportion of U.S. youth with type 2 diabetes is projected to increase by 49% by 2050, with the greatest increase in racial/ethnic minority youth.³

Weight loss, and to a lesser extent increased physical activity, have been proven to prevent or delay diabetes among overweight or obese adults with pre-diabetes.⁴ Surprisingly, there are no similar proven interventions to prevent or delay diabetes in youth, in part because few lifestyle modification interventions have focused on diabetes prevention in youth. There is a compelling need for such interventions, particularly those that could be sustained in the low-income, minority communities whose youth are at highest risk of diabetes.⁵

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Peer-led education programs that promote lifestyle changes and weight loss represent an effective low-resource diabetes prevention strategy for adults in high-risk communities.^{6,7} Research suggests that like adults, young people are more likely to hear and personalize messages, and thus to change their attitudes and behaviors, if they believe the messenger is similar to them and faces the same concerns and pressures. Youth peer-led interventions have been shown to be effective in other behavioral interventions, such as sexual health and substance abuse prevention programs.^{8–10} Peers also influence important weight-related behaviors in adolescents including participation in sports and other exercise, screen time and fast food and sugar-sweetened beverage consumption.^{11–14} However, no studies have explored the use of youth peer leaders to deliver programs for diabetes prevention.

The “Practical Model” is the only theoretical model published to date that focuses specifically on diabetes prevention in ethnic minority youth.¹⁵ This model draws from several theoretical frameworks for behavior change, and empirical evidence from youth behavioral weight-loss interventions supports this model.¹⁵ To successfully translate the model into an effective youth diabetes prevention program requires formative research to understand health and disease beliefs, current practices, sources of support, social norms and perceived barriers to healthy lifestyles in specific target populations. Thus, we conducted focus groups with minority adolescents at risk for developing diabetes to explore their perceptions of disease risk, barriers and facilitators to adopting lifestyle changes, and ideas for program design (including identification of desired program leaders, preferred format for program delivery and issues to be addressed in the program). This paper presents the major themes from these focus groups framed in the context of the Practical Model. An expansion of the model is then presented with a description of how the expanded model may help identify and organize components of a youth diabetes prevention program for diverse communities.

METHODS

Participants/Recruitment

The study was conducted in East Harlem, a predominantly low-income, non-White neighborhood in New York City. Program directors at four community-based after school programs provided basic information about the study and identified interested adolescents, and eligibility was then assessed (age 14–18 years, no personal history of diabetes, positive family history of diabetes in a parent or grandparent, residence in East Harlem and no current pregnancy). Eligibility criteria were chosen to select adolescents at high risk for developing diabetes. Participants were recruited as per an institutional review board–approved protocol including caregiver consent and participant assent. The researchers recruited 21 teens and held four focus groups at the collaborating community sites, with each group including a mix of younger and older, male and female, and Black and Latino adolescents, representing the diversity of East Harlem. Ongoing data analysis indicated that theoretical saturation was achieved after completing four focus groups so no further groups were conducted.

Data Collection

The research team began by informally interviewing 10 adult community leaders who work with youth to identify topics for exploration in the focus groups, including feasibility of employing the peer model for adolescents, perceptions of diabetes risk, identification of community assets that could be incorporated and the appropriate context for the intervention. Using this feedback, literature review, consultation with national experts in youth behavior change, and guided by the “Practical Model”, a draft moderator’s guide was developed. Researchers pilot tested questions with 5 adolescent volunteers from the collaborating community sites, assessing for understanding by having them rephrase the questions in their own words, and then made minor modifications to finalize the guide. The moderators used a semi-structured format with open-ended questions initially, followed by probes. Each group was 60 to 90 minutes long and moderated by two trained staff, audio-taped and transcribed verbatim.

Data Analysis

Two coders (authors JC and NV) developed a list of inductive and deductive codes using Grounded Theory¹⁶ and open coding techniques. Preliminary codes were refined through consensus until coders agreed on specified definitions for each code. Final codes were applied to all four focus groups, with an inter-rater reliability of 92%. Codes, quotations and field notes were used to identify four dominant themes based on comments made by multiple participants within and across focus groups.

RESULTS

Twenty-one adolescents (8 boys and 13 girls aged 14–18, 60% Hispanic and 40% African American) participated in four focus groups with three to eight adolescents per group. One group was comprised of three boys, the remainder were mixed gender.

Themes centered around understanding of diabetes and its impact, typical lifestyle behaviors, motivations for diet choices and physical activity, and social influences on lifestyle.

Theme 1: Adolescents have a limited understanding of diabetes, its physical complications and diabetes prevention, and focus their concerns instead on the burden of diabetes self-management

Participants demonstrated limited knowledge of the definition, causes, prevention, treatment and complications of diabetes. Most did not understand the difference between type I and type II diabetes, and were only aware that diabetes has something to do with how much sugar is in the body. Although they recognized the importance of preventing diabetes, ideas on how to prevent it were limited to vague dietary actions (“I watch what I eat”), with no mention of weight loss or increasing physical activity as ways to prevent or control diabetes.

Participants characterized consequences of diabetes primarily as tasks that negatively impact lifestyle, rather than as physical illness or disability. In fact, activities many adults would

equate with self-management (checking sugars, taking medications, and seeing doctors) were labeled by the adolescents as burdensome consequences of the disease. One girl stated,

“Like, if you eat a lot you’ll get scared,... because you’re going to have diabetes. That’s a responsibility, ‘cause you have to take your blood pressure, your sugar, and everything. So personally, I wouldn’t want to go through that. That’s just too much work.”

In all four groups, adolescents identified dietary change as the most salient negative consequence of having diabetes. One adolescent said,

“Like my friend before she got diabetes they told her that she was on the verge of getting it and she still went out and started eating McDonald’s, getting chocolate 24/7. And then she got diabetes and that’s when it really hit her, like, oh, my God, like, I’m not going to be able to be a kid again...”

Other consequences of living with diabetes mentioned included having less energy, not being able to play, and feeling sad.

Theme 2: Although adolescents perceive that dietary modification is the only way to prevent or control diabetes, regulation of diet is antithetical to their usual lifestyle

Participants stated that adolescents generally have unhealthy diets, with typical diet routines ranging from eating all day to skipping meals and then bingeing. One girl said,

“Like when I wake up, I eat cereal. When I’m on my way to school, I stop by the store and get a bacon, egg, and cheese. Then—no for real. Like this is a daily routine. And then, at lunch, I buy like \$3.00 in candy. Then when I get out I buy like two slices of pizza and then go to McDonald’s and eat too. And then when I get home, eat the food my mom cooks. And then eat candy. And then at night I’ll eat another bowl of cereal.

MODERATOR: Why were you guys laughing?

GIRL: ‘Cause it’s funny that we all do the same thing.”

Many adolescents reported regularly skipping meals because they were in a bad mood, did not want to eat in the morning, prepare food, pay for food, or did not have time or like the food selection. Skipped meals were often followed by overeating (i.e. double meals later in the day), particularly of unhealthy fast foods or junk food. Participants also mentioned craving unhealthy food and cycling between dieting and eating “mad food.” One boy said,

“Cause I can crave steak one minute. The next thing you know, I want some chips or, or, maybe like chicken or rice. So it depends on how I feel. And like BOY I said, it depends on your taste buds. ‘Cause you could just have this craving, I mean, your mouth could just start drooling like—

MODERATOR: How come?

GIRL: Because we’re teenagers. We want it when we want it.”

Theme 3: Adolescents' motivations for food choices and physical activity are largely determined by a combination of cost, mood, body image, availability and marketing, not health considerations

Most adolescents thought their risk for diabetes was low, did not link health with lifestyle, and did not feel that health concerns significantly impact diet or exercise choices. One boy said,

“I know teenagers don't care because...we had to go to this workshop and we had to watch what's in sodas and why we should choose to be healthier. After the event everyone was like 'I don't care. I'm still going to drink a soda.'”

Instead, several other drivers of lifestyle behaviors were identified. Youth identified *cost* as a major determinant of exercise decisions and food choice, equating exercise with joining an expensive gym, and relying on small amounts of pocket money from their parents for snacks and thus prioritizing large, inexpensive portions over nutritional considerations. One participant said,

“...if you want us to eat healthy, why make it more money? Just because like a slice of pizza will be like a dollar 25, it's cheaper than like getting a salad.”

Participants reported that *mood and emotions* also impact lifestyle, with sadness and anger commonly associated with unhealthy behaviors. One girl stated,

“I eat when I am, like, sad or when I need to get over something, because food makes me happy. So like, when I'll argue with my mom...then I'll just take a bag of chips and go to the room and lie down and just watch TV.”

Lack of energy (due to school work or lack of sleep) was one of the main reasons for not exercising. Teens rarely mentioned activity as a way to improve mood.

One major motivation reported for healthy lifestyle choices was to look better and improve *body image*. Body image was identified as a common source of stress because teens want to be perceived as attractive by their peers. One girl said,

“I'm getting to where I don't want to be walking down the street waddling 'cause I can't hold my weight. That's not cute.”

Finally, *environment* was cited as a major determinant of food choices and physical activity behaviors. Adolescents described being surrounded by unhealthy food options. Their schools serve food that is “bad”, “old”, “spoiled” or “frozen,” so they skip meals in school and buy inexpensive foods outside school at an overwhelming number of surrounding fast food and junk food venues. One participant said,

“...it's all around us, like everywhere you go there's a store that sells something that isn't totally healthy, and if you have a little bit of money, and you're hungry, you're going to buy whatever you find there...It's hard. It makes you want to cry.”

Teens also described a sense of a food conspiracy, the idea that unhealthy foods are concentrated and advertised in poor and minority neighborhoods, often specifically targeting young people and including misleading information about food content or risk.

“...they put a lot more fast foods in the lower incomes communities because they know that they can’t afford healthy foods. So they do that on purpose.”

As compared with more affluent communities, they also described their neighborhoods and schools as having limited safety and physical space to exercise.

“And some people’s neighborhoods are dangerous, they might not want to go outside past a certain time. Or they might just go straight home from school, so they don’t get hurt or something.”

Theme 4: Social pressures reinforce sedentary behaviors and unhealthy diets, with minimal counteraction in the form of positive lifestyle support

Adolescents acknowledged social support from friends and family for healthy behaviors, but also reported significant social pressures to engage in unhealthy diet practices.

In terms of dietary social pressures from family, many said they simply must eat whatever a caregiver cooks, even if it is unhealthy or served in large quantities. One boy said,

“Like, if you go to your grandmother’s house she going to make you eat everything and it’s going to be all sorts of unhealthy foods and if you don’t eat it she going to make you eat it. And if you finish it too fast she going to come with another plate.”

On their own, adolescents reported choosing foods that require little preparation. One girl stated,

“My mom is lazy. She normally won’t even cook, so me and my older brother... we bring home what we want to eat. The fastest thing is Chinese food. So,..., we brought Chinese food and we ate it.”

In addition, participants cited difficulties with trying to eat healthier outside of the home only to come home and find unhealthy choices. One participant said,

“We go outside, get something healthy like a turkey burger or something, come back in and there’s Oreos on the table.”

Teens also discussed how it is difficult to talk to family members about weight control efforts, and challenges of having an overweight parent give guidance about dietary behaviors.

“If you try to tell your grandmother something you just going to get slapped. She going to think you trying to be disrespectful.”

Adolescents also faced social pressures from friends, relying heavily on social cues from peers when making lifestyle decisions. They want to eat what others eat, which is often unhealthy, and they want to be active only if their friends are.

“Like, I’ll be trying to eat healthy and everybody over here eating fast food and five cent chips with cookies so I’ll be like, if they eat it, why can’t I eat it?”

“...and like, I’ll tell my friends, like, once I went on my Facebook status. I said, who wants to be my jogging buddy? And nobody liked it... I don’t want to do it alone.”

Occasionally, adolescents reported finding peer support for healthy choices and modeling friends' healthy behaviors. Mechanisms by which peer support may encourage activity included making exercise more fun and interactive, being introduced to new activities, physically helping with the activity (i.e. lifting weights) and engaging in social activities like dancing.

Program design—Adolescents described characteristics of their ideal diabetes prevention program including: (1) An after-school group support program led by peers of either gender, 2–4 years older than participants, so they would be knowledgeable but still relate to participants; (2) A convenient community location; (3) A combination of instructors from Harlem who understand local challenges and outsiders who might have new ideas; (4) Peer leaders who are interesting, funny, fun, creative, open, honest, good listeners, and “real but not harsh,” who model the healthy practices they are trying to teach, use personal stories and provide feedback based on their own experiences; (5) Leaders who care about them and check up on them to make sure they succeed; and (6) Additional social support in between in-person workshops through the use of tools such as text messages and social media.

Methods for creating a comfortable learning environment included encouraging participants to speak their minds without being disrespectful, preserving confidentiality, focusing on healthy eating and active living, rather than on weight loss *per se*, having a good relationship with peer leaders, not diving into sensitive topics right away, and offering interactive activities.

Factors to encourage participation included joining with friends, providing free healthy food, access to free physical activity, and small gifts for attending (i.e., movie tickets). Potential barriers included embarrassment/stigma about being in a weight loss program, discomfort in sharing personal details, wanting to spend time with friends not in the program, competing demands, lack of energy, inconvenient location or timing, and most importantly, workshops not being engaging. Specific workshop components of interest included sharing success stories, goal-setting and self-monitoring, discussing types and quantities of recommended foods, and simple strategies to increase activity. Adolescents also felt the program should include advocacy to raise awareness and provide ways to give back to the community to help others stay healthy.

DISCUSSION

The study objectives were to understand minority adolescents' perceptions of their diabetes risk, examine barriers and facilitators to adopting lifestyle changes, and explore ideas for adapting a youth diabetes prevention model through the use of focus groups.

Some findings have been described previously. Similar to the few other studies that have examined knowledge of type 2 diabetes among at-risk youth,^{17–19} teens in this study had a limited understanding of diabetes, its symptoms, complications and connection with diet, obesity and physical activity. Adolescents viewed themselves as ‘unhealthy eaters’ with a normative preference for unhealthy foods,²⁰ and knowledge regarding healthy foods does not adequately counteract these difficulties in adopting healthier diets.²¹ Youth continue to

skip meals and purchase unhealthy snack foods, soda and fast food because of ease and low cost.^{22–24} Thus, despite knowledge about healthy diets and recognition that dietary modification is an important part of preventing and controlling diabetes, adolescents rarely limit consumption of foods based on potential health effects²¹ unless there is a perceived critical, immediate threat to wellbeing.²⁰

Several new findings also emerged from this study. Youth at risk for diabetes had expectations of challenges they might face should they develop diabetes that were markedly different from those described by youth who have already developed the disease. The most anticipated negative consequences of developing diabetes were dietary change and burdensome self-monitoring behaviors. In contrast, adolescents already diagnosed with diabetes state that adopting these self-care behaviors did not require a big adjustment in lifestyle, and were more concerned about embarrassment, fear of rejection, difficulty in maintaining diet when around others and needing more time to perform these behaviors.^{25–27} Also, in contrast to adolescents already diagnosed with diabetes,^{26,27} few adolescents in this study voiced concerns about the physical consequences of diabetes. Those who had observed complications of diabetes in family members, such as limb amputation or loss of vision, however, expressed greater motivation for preventive measures. These findings suggest that teens at risk for developing diabetes may need to be motivated based on both perceived consequences of living with the disease and teen diabetics' actual experiences.

Like other studies, several barriers and facilitators for healthy eating and active living were identified including taste, time, availability and cost constraints, mood/stress, lack of motivation/energy, and neighborhood factors.^{20–22,24,28–34} An important new finding is that teens view these deficiencies through an equity lens. Teens commented on disparities in access to healthy food, exposure to advertisement for unhealthy foods and lack of safe spaces to be active compared to more affluent neighboring communities. These perceptions are certainly not without merit, given the abundant evidence that such disparities do in fact exist.^{35,36} Thus it may be worth exploring how to harness these beliefs and appeal to this sentiment of unfairness to engage youth in lifestyle changes and to promote youth advocacy for environmental change.

Similar to findings in this study, others have described how peer considerations may supersede personal judgment to eat well,²⁸ how peer interactions increase both the availability of unhealthy food and the social pressure to eat it,^{14,21,24,30,37} and how friends may make negative comments when one tries to eat healthy.³⁸ Previous studies identified family support (including cohesion, modeling and monitoring) as a positive influence on lifestyle behaviors,^{24,39} but youth in this study spoke mostly about the negative influences of both family and friends on their behaviors. Family members impeded healthy behaviors through provision of unhealthy foods, pressure to eat large portions, and lack of support for weight control efforts. Interventions should thus consider equipping adolescents with tools to deal with social pressures from friends and family that thwart healthy lifestyle change. In addition, incorporation of peer educators may increase social support and provide positive role models for behavior change.

Adaptation of Youth Diabetes Prevention Model

Based on study findings, the “Practical Model” for diabetes prevention was adapted with suggestions for implementation (see Figure 1 with terms from the model bolded in below discussion).

Focus group findings suggest that **knowledge** is necessary but not sufficient for behavior change. Increasing awareness of personal diabetes risk (to increase **perceived susceptibility**) and connecting this awareness with the perceived impact of diabetes may be helpful, since adolescents are concerned about potential negative consequences of the disease. To focus on teen motivators which are not health related (including body image, mood/stress, economics, and social supports), group discussion with brainstorming and problem solving may help teens recognize the impact of these factors on behaviors and health (**outcome expectations**) and develop their own strategies for addressing them. For example, one activity suggested in the focus groups was to use magazine cut outs to discuss media images of health/beauty followed by discussion of ideas for maintaining healthy body image or brainstorming ideas for alternatives to binge eating when angry or upset.

Diabetes prevention programs for teens should also address perceived norms (**normative beliefs**) around adolescents’ dietary and physical activity behaviors. Adolescents acknowledge that dietary regulation is one major strategy for reduction of diabetes risk, but they identify their dietary behavioral norms as erratic and hard to change. Participants suggested that setting goals and monitoring behaviors could help them slowly become healthier, and previous studies also suggest that goal setting may be an effective strategy for behavior change in young people.⁴⁰ Related to this, **self-efficacy** is another important determinant of behavior change in youth.^{41,42} As perceived barriers have been shown to mediate the relationship between self-efficacy and behaviors, programs could specifically address behavior change barriers-first recognizing them, and then developing strategies to address them to slowly increase self-efficacy for behavior change.⁴³ This may be achieved through brainstorming, self motivation and self management exercises, setting and accomplishing goals, group problem solving, praise/verbal exhortation, and building coping skills.^{44,45} For example, teens suggested that they could discuss “things that make it hard to eat healthy” or “things that make it hard to stay active” and then make a specific goal to deal with one of the challenges over the next week or discuss possible strategies to address these challenges as a group.

The current study found that **social influences**, including largely negative influences from both peers and family members, are one of the most important determinants of behaviors. Programs could include problem solving and communication strategies for dealing with social pressure for unhealthy behaviors from friends and family, using interactive activities such as skits and role play.⁴⁵ Teens endorsed the proposed peer education model which inherently involves building a social support network to promote healthier behaviors, peer role modeling, and opportunities to learn through vicarious experiences. Teens also suggested that support may extend beyond the inperson sessions using strategies such as group text messages,^{46,47} interactive websites,^{48,49} and communication through online or mobile social networks.

Finally, study findings suggest that **environmental factors** are a major consideration for diabetes prevention in minority youth. Youth first need to recognize environmental barriers and opportunities for healthy eating and active living and may then use activities such as brainstorming, problem solving, and partnership with community organizations to address them.⁴⁵ For example, teens suggested that they could brainstorm ways to make healthier choices at fast food restaurants or free opportunities to be active in the neighborhood. This awareness as well as teens' discontent about environmental disparities may be leveraged to engage youth in lifestyle change and to promote youth advocacy.⁵⁰

Limitations

There were several study limitations. Individuals may not fully disclose information in group settings and participants may be unduly influenced by the ideas of others. The small sample size may not have allowed recognition of all relevant facilitators, barriers and ideas, although theoretical saturation was achieved. While there are developmental and other differences between 14 and 18 years which may have impacted results, the decision was made to target high school age programs with the plan that these same programs would later be the focus for the developed program. Youth leaders in partner organizations helped recruit participants which may have skewed the participant sample, impacting generalizability. However, this study was designed to inform a youth diabetes prevention model for this specific community, rather than to define beliefs in the general population or for all ethnic minority adolescents. Finally, since there was no information about body measurements, diet, physical activity or education level in focus group participants or their parents, impact of these factors on study results could not be examined.

IMPLICATIONS FOR RESEARCH AND PRACTICE

There is a need for formative research to allow youth opportunities to inform interventions designed to impact them.^{37,51} Important considerations in program development include who teens identify as the desired messengers (slightly older peers) and how to deliver messages (through a combination of in-person group workshops and technology based tools). Other general considerations include ensuring confidentiality,³⁷ convenient program location,⁵¹ recognition of competing demands,³⁷ reducing obesity related stigma,^{37,51} and making programs fun/interactive.⁵¹ Using focus group results, researchers worked with community partners to tailor a youth diabetes prevention model. Study findings helped identify potential program components related to constructs in the model. These include use of peer led educational workshops incorporating: 1) mini lectures and games about diabetes, healthy eating and physical activity, 2) discussion of personal diabetes risk and negative impact of the disease, 3) brainstorming and problem solving to address non-health related determinants of behaviors and barriers to healthy lifestyle, 4) recognition of usual adolescent behaviors and changing them through goal achievement, 5) group activities and technology/social media to build social support and address social pressures for unhealthy behaviors, and 6 addressing environmental barriers and inequalities through group activities and youth advocacy efforts. Future work will focus on implementation and evaluation of programs developed based on these findings.

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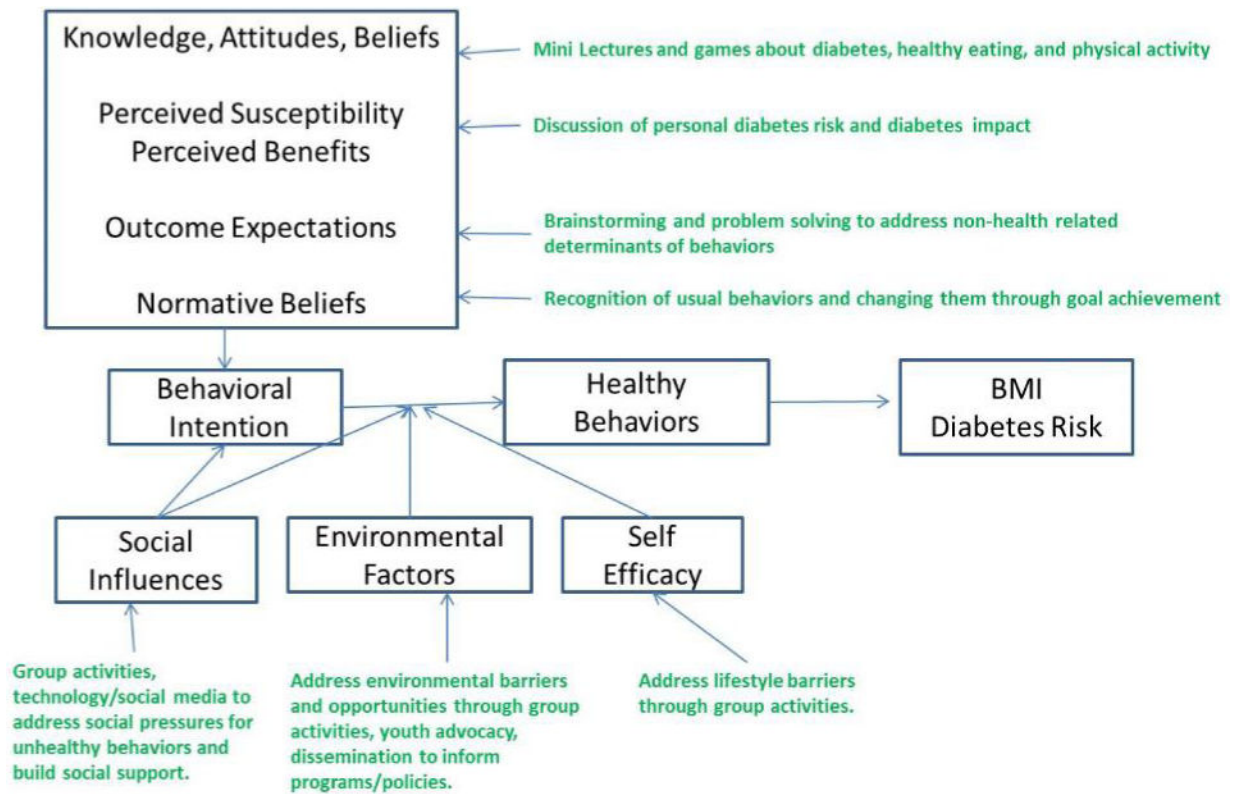


Figure 1.

Note: Model theoretical constructs are presented in boxes with related potential components of youth diabetes prevention intervention in green